

Psychosocial implications of type 1 diabetes mellitus among children in India: an emerging challenge for social work profession

Abstract

One of the widespread childhood chronic illnesses, which is seldom talked about is type 1 diabetes mellitus (T1DM). The discussion on T1DM is often missed because the emphasis is majorly on the adult DM or type 2 DM which is a lifestyle disorder. T1DM occurs at an early age and is a lifelong insulin deficiency. The treatment and the strict regime lead to numerous psychological and social repercussions for the child (patient) and the caregivers. The implications vary from issues in family, at school, at social gatherings, often creating behavioural disorders. These implications further affect the patient's health, DM self-care tasks, glycaemic control, and adherence to treatment. It is important to create awareness among people that chronic illness often causes negative psychological and social consequences but one needs to learn to cope with them. T1DM is not just about insulin shots and blood tests; but much beyond it. It requires proper understanding and support which has to be provided by professionals other than doctors. This paper looks at the prevalence of the disease, the implications for the child and the caregivers, and discusses T1DM as an emerging challenge for social work profession.

Keywords: Chronic Disease. Insulin Deficiency. Caregivers. Medication Adherence. Coping.

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Received: 7 December 2015
Revised: 7 January 2016
Accepted: 16 January 2016
Epub: 27 January 2016

DOI: 10.5958/2394-2061.2016.00016.1

Introduction

Diabetes mellitus (DM) is well-known across the globe as a pandemic which needs to be tackled on a priority basis. It has been listed as a lifestyle disorder as it has much to do with the sedentary life that many people are living in the new global techno-economic world. DM is classified into two broad and mostly exclusive categories, namely type 1 and type 2. The one most commonly talked about in the context of present day lifestyles and dietary changes is type 2, being mostly an ailment reported among adult populations. Discussions on DM most often miss out on taking stock of a category of diabetics who although in minority are no less important. Mostly children, the type 1 DM (T1DM), comprise ten per cent of diabetics worldwide. The International Diabetes Federation's Diabetes Atlas (fifth edition)[1] projects a three per cent increase per year. T1DM is an endocrine condition among children where the beta cells in the pancreas do not produce enough insulin for the body. This is a chronic deficiency. According to the Diabetes Atlas (sixth edition),[2] more than 79,000 children developed T1DM in 2013 around the globe. The South-East Asia Region has one of the highest estimates of prevalence of T1DM in children with 77,900 affected. In 2013, an estimated 12,600 children under the age of 15 in this region developed T1DM. India accounts for the majority of the children with T1DM.

The Diabetes Atlas (sixth edition)[2] reports the regional prevalence of T1DM. An estimated 24% of all T1DM children are in the European region. The developed countries like the European nations, the United States of America (USA), Canada, Australia, New Zealand, Japan, Singapore, Saudi Arabia, and other high-income nations have nearly 46% of the T1D population. India is estimated to have 97,700, China 8,700, and Africa has an estimated 36,000 persons with T1DM.

It is expected that the total prevalence of people with T1DM will increase in the coming years. In developed and high income countries, children with T1DM have proper access to healthcare facilities and the latest medical technology to manage their DM. On the other hand, in countries which are not developed or belong to the low income category, access to healthcare is poor and families face various challenges when it comes to dealing with a chronic illness like DM. Moreover, even detection and reporting of the cases of T1DM is poor, thus leaving many to not being able to cope and manage the disease.

India being the second highest populated country in the world reports of a significant number of children with T1DM. There is wide diversity among class, caste, and religion in India. Different population groups have different practices. Apart

from the socio-cultural differences, the number of poor and illiterate people is also very high. All these factors influence the access to health services, treatment procedures, and management of health. In case of DM, lack of access to medical facilities, costly insulin, inadequate medical and psychological support, insufficient DM education, and extreme poverty all lead to poor outcomes. Poor or delayed diagnosis, incorrect treatment, lack of drug adherence, irregular medication leads to complications and in some cases death. Apart from these factors, in a country like India, where most of the people are driven by superstition and religious beliefs, children are also exposed to various alternative treatments and complimentary medication. Lack of knowledge and awareness often leads to worsening of the child's health and various other medical complications. Poor control leads to impaired quality of life as children often miss school, drop out of school because of ill health, and are unable to cope with the demands of the school curriculum. There is stress and tension in family, difficulty in peer relationships, and poor social intermixing. Many who grow up face ongoing challenges of adjustments to college life and to demands of the workplace.

In India, the contemporary public health agenda calls for various transitions which are an outcome of the epidemiological, demographic, and environmental changes. The rise in the burden of non-communicable diseases is now the major cause of increasing mortality and morbidity. According to Lakshminarayanan,[3] non-communicable diseases often lead to premature deaths due to chronic disability and ill health. It then emerges that progressive countries take stock of such situations and develop programmes to address these concerns. Also, the broad domain of public health is concerned with disease prevention and control at the population level, through organised efforts and informed choices of society, organisations, public and private communities and individuals. These initiatives need to be appropriately designed to meet the emerging concerns.

In this regard it is important to first understand the ramifications of T1DM in the life of a child in the context of his school and family life. Quite understandably the demand for a strict diet, blood sugar testing, and insulin injecting pattern round the clock takes its toll not only on the child but also on the care providers. An understanding of these impacts on the family is important for the medical professionals and others who engage in the teamwork for DM management. These can be the psychologists, social workers, teachers, and the nutritionists. It may be stated here that the school teachers have a critical role to play as a large part of the day of each child is spent in school. It is in school that the child faces different challenges such as to manage hypoglycaemia because of excessive physical exercise or not being able to eat or share the lunch which friends bring from home. Peer relationships also suffer as many times the DM child is unable to attend school on a regular basis.

The present paper looks into these psychosocial concerns that a child with T1DM has and investigates the concerns for professional social work practice. The urgency of the situation needs to be underscored. It goes without saying that each child is precious and these lives have to be treasured. This is especially so because DM management, especially

among children, is not a patient concern alone, it is as much a concern of the family and the school. These are the places where an enabling context for the child needs to be created to live happily and learn to manage his/her ailment well. This forms the crux of success in management of DM, as DM is a disorder that can to a large extent be managed and controlled, with medication and lifestyle changes. This no doubt should be taken as a 'preferred' choice of families till research brings forth better options and children are made free of blood sugar testing and insulin injections multiple times a day.

Review of literature

The review of literature first highlights the research in this area and the psychosocial impact of T1DM on children and families, both in India and abroad.

Around the world, in recent times, issues of public health have been receiving significant attention of researchers. Public health is constantly evolving with new concerns arising and new developments emerging to address old issues. Public health has always been about providing services for vulnerable populations, either directly or through the healthcare system. But this is only one of the areas of public health.[4] Interventions like hand washing, food and drug safety, controlling air pollution, and vaccination against childhood diseases are a few other areas that fall in the purview of public health. Public health has been defined by Winslow (1920) as "a science and art of preventing disease, prolonging life and promoting health through organized community effort. The goal of prolonging life is complemented by emphasis on the quality of life through treatment and prevention of diseases." [5]

Talking about diseases, the focus has always been titled towards the communicable diseases like tuberculosis, malaria, acquired immunodeficiency disease (AIDS), and alike but in the recent years the emphasis has shifted to the non-communicable diseases like cancer, DM, and cardiovascular illness. Modern public health can be looked at as the totality of all evidence based public and private efforts that preserve and promote health and prevent disease, disability, and death.[4] In order to achieve this, public health practice requires a multi-disciplinary approach which involves team work of professionals from various specialised fields like physicians, psychologists, medical officers, social workers, nurses and midwives, etc.

T1DM is a complex disorder which involves major changes in lifestyle for the patient and the family, posing enormous lifelong stress. It is characterised by hyperglycaemia when the insulin producing beta cells in the pancreas produce little or no insulin. This usually occurs at an early age. The child with insulin deficiency has to take insulin externally in the form of subcutaneous injections. The lack of insulin affects carbohydrate metabolism and also causes protein and fat abnormalities, and requires major lifestyle changes to reduce the risk of both short-term and long-term complications. The lifestyle modifications include blood glucose monitoring, dose adjustment, regular insulin shots, diet and exercise regimen. Marshall *et al.*[6] state that families raising children and youth with T1DM report that the entire family is affected by the disease, and a major challenge for them is to

live normally. A study in USA by Freeborn *et al.*[7] looks at the hardships faced by children and youth with T1DM. The authors categorise the main challenges faced by children into three categories: Low blood sugar, self-care activities, and feeling different/alone. According to this research, identifying low blood glucose, having someone to help at that time, then managing it and knowing activities that cause low blood sugar, were the main challenges for the children. The children complained of missing various school activities because testing and injecting consumed all their time. Some could not even eat their lunch at school. Children and especially adolescents often manipulated their bolus doses as they found it inconvenient to adjust the dose every time they wanted to eat. Another challenge was to have someone to help at the time of having low sugar or hypoglycaemia. Participants reported that when the sugar dropped they felt cold and weak. Children do not like to miss their activities or games because of hypoglycaemia. Similarly, self-care activities which include testing and administering insulin are also a challenge because of pain and inconvenience. Participants with insulin pump find it easier to manage their dose as compared to those on injections.

Freeborn *et al.*[7] further report that those suffering from T1DM have a feeling of being different and alone. Being singled out is a major concern. Participants in their research reported that parents visiting school during lunch break or otherwise made the children feel awkward and embarrassing. They had a fear of losing friends and also of being discriminated because of DM. According to Peters *et al.*,[8] feeling singled out and uncomfortable did not just cause psychosocial difficulties, but caused children with T1DM to being less adherent to self-care behaviours which resulted in poorer metabolic control.

Further, Freeborn *et al.*[7] conclude that it is the responsibility of the nurses to educate and create awareness among parents and children about hypoglycaemia and its management. They should talk with young people about balancing blood glucose management and participating in activities. For example, Freeborn *et al.*[7] discovered when youth were given flexibility in deciding how to manage their self-care procedures, they had better glycaemic control. It has to be done in a way that children feel normal about it.

Addressing psychological issues is critical for optimal management. In a country like India and other highly populated nations, it is usually observed that physicians have a time constraint to deal with these issues as the emphasis is more on the medical treatment and catering to maximum number of people in limited time. Consequently, treatment compliance often suffers because of inadequate guidance on coping and stress management.

Hilliard *et al.*[9] emphasise the increased risk of anxiety and depression among the adolescents and teens. Psychological issues like stress, anxiety, etc. complicate the DM management process, and distract from the blood glucose monitoring and lead to suboptimal glycaemic control. Universal recommendations for routine psychological screening has been emphasised for teens with T1DM due to the elevated risk and consequences of psychological symptoms.

The results of the study by Hilliard *et al.*[9] show that the higher the anxiety symptoms, higher is the glycated haemoglobin (haemoglobin A1c, HbA1c) value, while depressive symptoms lead to reduced blood glucose monitoring and poorer quality of life. All this can come in the way of successful DM self-care. According to the authors, depression and anxiety scores have different link with blood glucose monitoring and HbA1c, but in a general sense, both represent psychological distress and have a negative impact on management of DM and self-care tasks.

There are a number of researches which have been conducted in the Western context but there is a paucity of information regarding childhood diabetes in India. A small study by Prasanna Kumar *et al.*[10] on the awareness, management, and challenges of T1DM in the current scenario in India looks at the presence of the illness among children, the high mortality rates attached to it, and the challenges the country faces in order to manage the burden of this disease. The study reports that T1DM, if left unmanaged and uncared for, can substantially reduce the life expectancy. In the Indian context, the challenges are different from that in Western countries. Here, the first challenge is lack of awareness about the disease among the general public. DM only refers to type 2 or adult DM for the majority of the population in India. According to Prasanna Kumar *et al.*,[10] the awareness level is also very poor among the public health professionals as their curricula do not lay much emphasis on T1DM. Another challenge is the psychosocial aspect of childhood DM which manifests itself in a different way than that in the more developed countries. In India, because of extreme poverty and lack of access to available resources, patients with T1DM at times fail to understand the severity of the blood sugar level and focus more on the incentives provided by the social workers or the healthcare workers.

Apart from this, the diagnosis of T1DM was another challenge a few decades back but the situation has improved today with new facilities and diagnostic tests available. But the infrastructure and investigation facilities are very poor at the primary care level. In rural areas and especially for the poor, the availability and accessibility is a major concern. According to Prasanna Kumar *et al.*,[10] the utmost important aspect is the effective use and storage of insulin and in India, up to 80% patients lack insulin storage facility.

According to Prasanna Kumar *et al.*,[10] the planning and delivery of the DM management interventions by the government is also inadequate. The government health services are hardly equipped to offer services for management of DM. A major gap in the system is the paucity of data of T1DM patients in India. According to the authors, the data provided is an assumed number as it does not include every child detected with T1DM. The guidelines by the American Diabetes Association state that every newly diagnosed child should be assessed and evaluated by a DM team consisting of paediatric endocrinologist, a nurse educator, a dietician, and a mental health professional. In India, this type of team work is difficult but programmes like CDiC (Changing Diabetes in Children) is taking care of many children. They further report that there are about 70,000-75,000 children with T1DM in the country and the CDiC programme is able to take care of

just 4,000 children. The study throws light on the role of this programme and the way in which it aims to achieve its targets of providing better infrastructure, inexpensive testing strips, and insulin, and improving the access and availability to those who cannot afford it. Prasanna Kumar *et al.*[10] emphasise the wide disparities of socio-economic levels, educational background, and availability of DM care which pose major obstacles in the management of disease in India.

Sudhir *et al.*[11] have looked at the psychosocial impact of a chronic illness like T1DM among the young patients and their families. They have provided an overview of various issues and problems, and the interventions carried on so far. According to the authors, chronic illness sets the adolescents at an increased risk for emotional stress and anxiety. Since T1DM occurs at an early age and is lifelong the psychological demands often exceed the capacity of the patients to cope with it. The authors state that management of DM is the toughest task at adolescence because of the developmental changes in the body which has its own challenges for the child. The children during adolescence are already preoccupied with the changes in their body, striving from freedom and independence, role and identity crisis, and peer acceptance and all this clashes with their coping with DM.

Apart from these issues which occur during childhood and adolescence, there are other problems which people with DM have to face. They might face discrimination in their professional arena or in matrimony and they may suffer from inferiority complex due to insulin deficiency. DM or any other non-communicable disease is still seen as a stigma in our society.

There are a few research studies which look into the emotional and psychological characteristics of insulin dependent DM and these researches often discuss about the ways in which patients can cope with the disease-related stress and anxiety. There is a need of multi-disciplinary approach to the management of DM which involves the endocrinologist, a diabetes educator, a social worker, a psychologist, and a dietician. In this context, the present paper gives an overview of the psychosocial implications of T1DM among children in India and then deliberates upon the role professional social workers can play in this regard.

The social work profession is based on the humanistic and person centred approach that emphasises the uniqueness of a person and their life experiences. When children are diagnosed with T1DM, they and also their parents get affected in several ways. Their confidence, self-esteem, sense of being and control may be challenged. The world turns upside down for these families. At this juncture, support from various sides becomes essential for the family to cope with a chronic illness. This can be in the form of extending physical and in some cases financial support. Equally important is the psychological support that may come from close family, friends, or the healthcare provider.

A crisis situation can occur at any time. Sudden change, deterioration in health or any other factor can provoke strong fluctuations in a person's emotional state. There is data which suggests that poor adjustment to diabetes can be related to rigid beliefs, poor social support and poor coping strategies.

Social workers intervene in many different ways in order to provide relief to the patients. One of these is counselling. Talking about one's fears, anxiety and other emotions can help resolve problems. Counselling is a process of face to face interaction which can help the patient to open up about his/her thoughts and feelings and reduce the impact of negative ideas, assumptions or irrational fears. It helps in better coping. There are other techniques like family therapy, home visits and referral services that are provided by social workers.

Despite possessing these skills of helping people and providing support to them, public health issues are still a challenge for the social work professionals. There is dearth of social work professionals in India and those who are available are not trained in handling health issues. The social workers who possess skills and training can work wonders in improving the mental as well as physical health of individuals in the society.

Implications

DM is a prolonged disease both in terms of the number of persons affected and the associated morbidity and early mortality. T1DM is an auto-immune, life-long, and chronic disease in which there is a deficiency in the insulin producing beta cells. It usually, not always, occurs during childhood or at a very early age. If not treated, people suffering from T1DM can develop severe metabolic disturbances, including diabetes ketoacidosis (DKA) and dehydration, leading to death eventually. If DM is managed properly, deaths from DKA can be prevented. DM management is possible through the insulin treatment which is the only treatment at present. Being a chronic ailment and occurring at a very early age, it has various implications on the family of the child, the parental roles and responsibilities get disrupted, and there is fear, anxiety, and stress. At each life stage, the impact on the child and family may throw up new challenges. Some of these challenges are contextually discussed below.

Initial stage (post diagnosis)

The news of the diagnosis of the child being diabetic brings with it feelings of shock, despair, denial, and fear. Most of the parents, whose child is diagnosed with DM, go through a phase of trauma and severe setback. Parents must come to terms with having a child with a life-threatening illness, and carrying out a labour-intensive and complicated daily regimen. The relationships in the family also go through turmoil as there is a huge amount of stress in the initial phase. There are role and responsibility conflicts and stress between spouses. There are different challenges that the patient faces at different life stages. When the child is too small the issues which arise are different than that of a teenager. A small child is unable to express as to what is going on his/her body. There are problems as the child is not able to tell about hypoglycaemia. There is no fixed pattern of eating or physical activity and therefore dose adjustment becomes a troublesome task.[12]

Parental concerns

A research by Whittemore *et al.*[13] looks at the psychological experiences of parents of children with T1DM and describes

the psychological distress in parents, to be associated with inconsistent discipline, lower parental involvement and warmth, lower family adaptability and cohesion, and higher family conflict. In contrast, higher parental anxiety was associated with higher maternal control and over protectiveness. Also the night time sugar monitoring has been associated with higher parental stress and anxiety, particularly in parents of young children. The authors report that the family life was completely disrupted as life revolved around caring for the child with T1DM. New routines had to be established and social isolation occurred due to the perceived need for structured and highly monitored care. Parents also had a fear of loss of a healthy child, control, freedom, and their ability to protect their child from harm, and these fears were not only during the initial days but were still present for many parents one year after diagnosis.

On the other hand, pubertal changes during adolescence lead to a lot of temper tantrums which make management of DM a challenge. A research in Australia by Moore *et al.*[14] reports that 11% of parents said their adolescent argued very often, 23% often, and 39% sometimes, while 44% said their adolescent had tantrums or showed hot temper (seven per cent very often, eight per cent often, 29% sometimes). Over half (53%) said their adolescent caused tension in the home, or was a source of arguments (54%). The adolescent phase is difficult to manage as young people are striving for independence and DM management comes as an additional burden. This often leads to child-parent conflict and eventually to non-compliance and non-adherence to self-care activities. They further indicate that the adolescents can feel they are not being trusted, especially when they are trying hard to maintain good self-care regimes but do not always successfully manage the difficult task of satisfactory metabolic control. Adolescents can feel the unfairness of having to curtail their activities in ways not understood by peers. These feelings can give rise to anger, anxiety, or depression, and further barriers to good family communication.

At school

One of the other significant challenges or implication of DM is on the child's schooling. Child DM is unlike the common cold which can be cured by a medicine in a few days. Instead it is a life-long deficiency and school is the first place of physical separation from the parents/care-providers. This is one of the most difficult tasks for the parents. Child on an average spends six to eight hours in the school, and this causes constant anxiety and fear in parents. There is a persistent fear of hypoglycaemia in school and also the panic about child's meal. Therefore there are high chances of missing school frequently because of lethargy, inactiveness, and fear of low blood sugar level.

Looking from the child's perspective, there is a fear of peer rejection and isolation in school. A child may feel different from other children and therefore not socialise with others. He/she might feel inferior to other kids. This thought and feeling often leads depression among children. These factors can influence school attendance, graduation rates, and educational attainment if the depression is not identified and treated.[15] If DM is not managed well and

if the blood glucose is not in control, the child will have problems in concentrating in class. A very low sugar and a very high sugar both will have an impact on the child's cognitive behaviour. Many children even complain of missing school recess or other activities because their time is consumed in testing their sugar and taking the insulin. This again impacts their peer relationship and causes stress for them. They feel ignored and have a fear of being rejected by their friends. Another challenge that children with chronic illness face is that of being discriminated. All people are not very sensitive regarding the illness and the lack of awareness about T1DM often makes the child suffer discrimination.[16] There can be restrictions on playing and going out on school trips. The children often feel uncomfortable in going out for parties or attending other social events either because they are treated differently or because the parents do not allow them to.

There are other challenges that the school poses to a child with DM. Most schools lack trained staff to manage DM and also have inadequate infrastructure to handle an emergency. In most cases, the teachers would not want to take an extra responsibility or might not be very cooperative.

Emotional and psychological problems

Sridhar and Madhu[17] discuss the psychological and cultural issues of DM in the Indian context. The psychological issues are more or less the same across countries but the developing and under developed countries suffer additional psychological burden because of the social and economic implications. They have discussed the psychological reactions at the time of diagnosis which include denial, anger, guilt, depression, and finally acceptance. These reactions can also occur at different life stages. The psychological reaction of acceptance might or might not occur and non-acceptance can lead to depression.[17]

The paper further discusses the children's beliefs about DM and its treatment as is important in influencing self-care, emotional well-being and glycaemic control. Similarly, the support of family and friends is an important source of good self-management. According to the authors, the frequency of telling others about the child's DM had the greatest impact on the parents. Another cause of concern is the normalcy of the overall growth and development of the child and also the long term complications. The authors[17] also emphasise the need and ways of coping with depression and anxiety. They list down various ways of coping like spiritual coping, joining social support groups, and taking professional help.

After schooling, people with DM often have to suffer discrimination in getting jobs. Since the general population lacks understanding of DM, people do not treat them as 'normal'. Another major problem that people with DM face is getting married. In our society, insulin dependence and lifestyle modification is seen as an additional responsibility and as a stigma. People with DM are sympathised with and pitied upon. This stigma is more pronounced for girls and women, and it comes as a double burden to them, one because of their health and secondly because of the inequalities perpetrated in male dominated societies. Families with lack of education, especially in rural areas, often do not let their

female children take treatment for DM because they want to keep it a secret. They feel it will bring shame to their family.

Thus, we can understand that a chronic illness like T1DM is not just about monitoring blood glucose and injecting insulin but it comes with a constant struggle on the social and emotional level. Let us look at the social and economic implications of childhood DM specifically in the Indian context. We all know the wide diversity and disparity that exists in our country. These wide differences also lead to difference in accessibility and affordability of resources.

According to Kalra *et al.*, [18] 25% of India's population lives below poverty line and the cost of DM care is high. The data in their research suggests that the direct medical cost to identify one subject with glucose intolerance is Indian Rupee (INR) 5278. The cost of insulin amounts to 350.00 US Dollar (USD) (approximately 16,000 INR) per year. Hospital treatment for DM claims 17% of the annual household expenditure in poor households, a majority of whom finance the expense through borrowing. Therefore DM is often called the 'disease of the rich' because of its expensive life-long treatment. [18]

Cultural and religious factors are responsible for influencing the DM management in India. The health behaviours are guided by the interpersonal environment and also the religious beliefs in many parts of the country. Endemic cultural practices hamper appropriate health related behaviours and make management of DM a difficult task. The low literacy level in the country also affects the treatment process. Lower the level of education and awareness about diabetes, higher is the level of HbA1c. [19]

Another implication of DM is people's preference for alternative and traditional medicine for curing DM. Since there is lack of understanding about the disease, many families use alternative or complimentary medication to treat DM as a supplement to insulin as well as a substitute. This often leads to complications as alternative therapies cannot substitute the effect of insulin. This may deteriorate the child's health and lead to further distress. A considerable number of patients (14%) still utilise the indigenous forms of medicine and one third prefers non allopathic medical systems for treatment. The reasons given for preferring traditional medicines were safety (31%), cost (30%), effectiveness (25%), and availability (11%). [20]

Therefore, lifelong illness like DM poses not only physiological implications but also impacts the social and cultural life of the child as well as the family and caregivers. It requires lifestyle and daily routine changes for the family after the diagnosis of T1DM. The child has to follow a fixed regime of testing, injecting, eating, and exercising. Even a slight change in the daily pattern may lead to major fluctuations in the blood sugar level which might not be an issue of concern in terms of the physical harm but can cause a lot of anxiety and stress in some parents. The everyday challenges that children have to face in school or anywhere outside home, lead to anger, frustration, and irritability in children.

It is very important to cope with these feelings because they eventually affect the management of DM and can lead to long-term behavioural issues as well. As per the guidelines

of the American Diabetes Association, and the International Federation of Diabetes, there has to be a team approach for the handling of psychosocial implications of diabetes. Physicians and paramedics will have to work in tandem in order to provide a physical and mentally healthy life to people living with DM.

Role of social work profession

As mentioned above, this paper takes a look into the role of social work profession in the context of T1DM. Social work profession is a broad area which branches into various fields like that of social development, social action, medical and psychiatric social work, and community development. It is a profession which is based on the concept of equality and justice. It aims at helping people by making them independent and also making them capable to voice their rights in the society.

Social workers therefore have various roles which include improving the quality of life and subjective well-being of individuals and groups. They have the skills of working with distressed families, old and young couples, children, youth, and communities. There are various specialised fields of social work like that of research, policy, direct practice, and other interventions for the benefit of those socially disadvantaged.

In the field of public health and non-communicable diseases, the role of social work profession is very important. The West has a multidisciplinary team approach which looks into the physiological, psychological, social, emotional, and educational aspects of any illness. A chronic illness like asthma or T1DM which occurs at a very early age can hamper the daily lives of the people suffering with it and also the caregivers. As discussed above, the repercussions of a chronic illness are major. Therefore a team of a doctor and paramedical staff is very much needed. The role of the professionals like a psychologist and social worker are important at diagnosis and continue after the diagnosis. Physicians are ill-equipped to deal with the psychological and social problems revolving around the illness which may be leading to non-adherence and non-compliance with treatment plans. In developing nations like India which has the second largest population in the world, the doctors especially in the government hospitals do not have enough time to cater to other needs of the patients except for the medical part of it. Therefore, we are in the urgent need of social workers and other paramedics to take care of the overall management of the patients.

The role of social worker can be explained through the following case illustrations:

Case 1: A social worker trained in T1DM was placed in a private clinic of a paediatric endocrinologist in Delhi. The social worker engaged with the patients to understand the issues they were facing and tried to bring a positive change in their current situation.

A 13-year-old girl visited the social worker in November 2013 with various issues related to teenage blues, peer problems, anger issue, and concerns with DM management. The first few sessions were spent in interacting with her in order to know her better and also make her comfortable with the process. Gradually, the bond developed and child started

opening up. There were issues related to adjustment with friends at school, testing blood sugars four times a day, and bringing the average sugar levels in control. She even spoke about her irritability, feelings of anxiety, and low confidence. The social worker took up the issues one by one. The skills of active listening and being non-judgemental enhanced the process of counselling.

The session included discussions, use of activity sheets, and some relaxation techniques. Gradually with time, the child became comfortable and many of the problems started to get resolved. The child started regular physical activity which helped her maintain her blood glucose and also reduce her irritability. She started checking her bedtime sugars which she never did before.

It was observed that the average HbA1c, post intervention, was better than the previous year's average HbA1c. This improvement can be credited to child's willingness and efforts to manage DM better.

Case 2: Another 15-year-old boy using an insulin pump had come to the social worker upon the doctor's referral with a set of different issues altogether. His parents complained that he did not interact with them at all. He stayed locked up in his room the entire day. He liked a girl in his school but had frequent fights with her and his other friends too. This child was depressed, and after sessions with him and his parents, he was linked to a psychiatrist by the social worker for further consultation. The child is now doing better with medications and sessions of counselling.

Case 3: A small case example can also be used to explain the skill of home visit. An adolescent girl aged 13 years who has DM for the last four years was facing issues in school with friends. This kept her stress levels high and therefore the blood glucose levels also fluctuated often. The social worker visited the house thrice for sessions with the child. These home visits took the comfort level of the client to another level and also helped the social worker to observe the environment at home. This process helped the client to open up and feel more secure.

Social workers and psychologists should be part of the interdisciplinary healthcare team. Team approach to DM care is a must. Team should include patient, DM specialist, primary care physician, nurse, dietician, paediatrician, psychologist, social worker, psychiatrist, family, and friends. Coordination among them is important.

A social worker can visit these families and discuss with families what challenges they are facing in living with DM. Each time, expectation and management goals can be reviewed and obstacles identified and solutions discussed. Success should be measured not only by glycaemic control as also by attainment of age appropriate DM-related skills and responsibilities. Professional social workers can work with parents and siblings, and promote opportunity to child to gain efficacy in self-management.

Overt psychological problems in young persons or family members should receive support from the DM care team and expert attention from mental health professionals. The DM care team should receive training in the recognition, identification, and provision of information and counselling

on psychosocial problems related to DM.[18] Stress management for child and parent at every stage of DM management is important. Ongoing screening for mother and child for symptoms of depression can go a long way in family coping.[18]

Social workers can help the child and family develop healthy coping skills. They can assist the family find solutions to day-to-day DM concerns and improve inter-personal communication. As and when required, they can connect the child and family with helpful community resources. They can also help the family find ways to manage the cost of DM and access low cost strips and blood test facilities. Further, they can provide counselling and therapy to the child or to family members when facing a crisis, mental health or relationship problems.[21] In this manner, they can promote positive family functioning and work on different aspects so as to enhance family cohesion, warm and caring DM support, and conflict resolution skills.

Conclusion

Although parents seem to be the primary source of support for DM care, friends are an important source for emotional support for adolescents with DM. It is with peers that the child goes out to play and tries new food. School teachers and parents can help strengthen these relationships and enhance the support the child receives in these peer groups. Given that education and support programmes to enhance self-management and improve positive psycho-social outcomes are hardly available, the role of the social worker to handle the myths and misconceptions that hinder DM care and management is important. In continuous contact with the family they can educate and inform those who play a significant role in the life of this child.

Finally, research is needed to understand the role of health beliefs, and the personal values which inform self-management and willingness to engage with DM care as recommended by healthcare professionals. Studies on family coping and school management of DM can guide further interventions. This would provide a firm footing to professionals working with children having T1DM and go a long way towards simplifying their concerns in daily life.

References

1. International Diabetes Federation. IDF diabetes atlas [online version]. 5th ed. 2011 [cited 2015 Dec 26]. Available from: [https://www.idf.org/sites/default/files/21991_diabAtlas_5th Ed.pdf](https://www.idf.org/sites/default/files/21991_diabAtlas_5th%20Ed.pdf).
2. International Diabetes Federation. IDF diabetes atlas [online version]. 6th ed. 2013 [cited 2015 Dec 27]. Available from: https://www.idf.org/sites/default/files/EN_6E_Atlas_Full_0.pdf.
3. Lakshminarayanan S. Role of government in public health: Current scenario in India and future scope. *J Family Community Med.* 2011;18:26-30.
4. Riegelman R. Public health 101: Healthy people - healthy populations (essential public health). Jones & Bartlett Learning; 2010.
5. Savage C, Kub J. Public health and nursing: A natural partnership. *Int J Environ Res Public Health.* 2009;6:2843-8.
6. Marshall M, Carter B, Rose K, Brotherton A. Living with type 1 diabetes: Perceptions of children and their parents. *J Clin Nurs.* 2009;18:1703-10.
7. Freeborn D, Dyches T, Roper SO, Mandelco B. Identifying challenges of living with type 1 diabetes: Child and youth

- perspectives. *J Clin Nurs*. 2013;22:1890-8.
8. Peters CD, Storch EA, Geffken GR, Heidgerken AD, Silverstein JH. Victimization of youth with type-1 diabetes by teachers: Relations with adherence and metabolic control. *J Child Health Care*. 2008;12:209-20.
 9. Hilliard ME, Herzer M, Dolan LM, Hood KK. Psychological screening in adolescents with type 1 diabetes predicts outcomes one year later. *Diabetes Res Clin Pract*. 2011;94:39-44.
 10. Prasanna Kumar K M, Saboo B, Rao P V, Sarda A, Viswanathan V, Kalra S, *et al*. Type 1 diabetes: Awareness, management and challenges: Current scenario in India. *Indian J Endocr Metab* [serial online]. 2015 [cited 2015 Dec 31];19, Suppl S1:6-8. Available from: <http://www.ijem.in/text.asp?2015/19/7/6/155339>.
 11. Sudhir PM, Kumaraiah V, Munichoodappa C, Prasanna Kumar KM. Management of children with diabetes mellitus -- psychosocial aspects. *Int J Diab Dev Countries* [serial online]; 2001 [cited 2015 Jan 2];21:69-76. Available from: http://diabetes.org.in/journal/2001_april-june/article2.pdf.
 12. Peter Chase H. Understanding diabetes. 11th ed. Denver, Colorado: Children's Diabetes Foundation; 2006.
 13. Whittemore R, Jaser S, Chao A, Jang M, Grey M. Psychological experience of parents of children with type 1 diabetes: A systematic mixed-studies review. *Diabetes Educ*. 2012;38:562-79.
 14. Moore SM, Hackworth NJ, Hamilton VE, Northam EP, Cameron FJ. Adolescents with type 1 diabetes: Parental perceptions of child health and family functioning and their relationship to adolescent metabolic control. *Health Qual Life Outcomes*. 2013;11:50.
 15. Cammarata C, Meyer KJ, Geffken G, Felipe D, Franz D, Vargas A, *et al*. Psychosocial issues that affect youth with diabetes. *Am J Health Educ*. 2009;40:277-81.
 16. Humensky J, Kuwabara SA, Fogel J, Wells C, Goodwin B, Van Voorhees BW. Adolescents with depressive symptoms and their challenges with learning in school. *J Sch Nurs*. 2010;26:377-92.
 17. Sridhar G, Madhu K. Psychosocial and cultural issues in diabetes mellitus. *Current Science*. 2002;83:1556-64.
 18. Kalra S, Sridhar GR, Balhara YP, Sahay RK, Bantwal G, Baruah MP, *et al*. National recommendations: Psychosocial management of diabetes in India. *Indian J Endocrinol Metab*. 2013;17:376-95.
 19. Nagpal J, Bhartia A. Quality of diabetes care in the middle- and high-income group populace: The Delhi Diabetes Community (DEDICOM) survey. *Diabetes Care*. 2006;29:2341-8.
 20. Singh P, Yadav RJ, Pandey A. Utilization of indigenous systems of medicine & homoeopathy in India. *Indian J Med Res*. 2005;122:137-42.
 21. Power T. Defining the role of social workers in diabetes care. *Diabetes Voice* [serial online]. 2002 Dec [cited 2015 Jan 2]. Available from: https://www.idf.org/sites/default/files/attachments/article_109_en.pdf.

Kakkar J, Puri S. Psychosocial implications of type 1 diabetes mellitus among children in India: an emerging challenge for social work profession. *Open J Psychiatry Allied Sci*. 2016;7:103-10. doi: 10.5958/2394-2061.2016.00016.1. Epub 2016 Jan 27.

Source of support: Nil. **Declaration of interest:** None.